

# PART TWO

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*P*art Two begins with a general overview of the family and some of the major problems, concerns, and issues typically associated with parents and siblings of handicapped children. Chapters Eight and Nine discuss some steps helpers may take in assisting these parents. A multivolume work would be necessary to cover a topic as broad and diverse as helping parents of handicapped children. The primary goal of this section is to raise some basic issues, indicate significant research, and encourage you to pursue additional areas that interest you.

This particular section assumes that you have a reasonable working knowledge of exceptional children and special education. Since Chapter One provided an in-depth discussion of this topic, the emphasis here will not be on the identification and characteristics of handicapped children. Instead, this section is directed toward identifying and understanding parental feelings as well as discussing how helpers can guide parents in resolving their problems by offering support, encouragement, workable suggestions, ideas, and basic information.

Part Two employs a primarily noncategorical approach. This framework is practical and useful because it eliminates the possibility of redundancy, duplication, and overlapping. Although admittedly this approach is imperfect, a discussion of parental reactions to mild/moderate and severe/profound handicapping conditions is best in a book of this size.

Using traditional categories may occasionally be necessary when dealing with such topics as genetic counseling and institutionalization, since both are traditionally associated with mental retardation. You may also expect instances when mild/moderate and severe/profound handicapping conditions may overlap, or may not be precisely clear.

I encourage you to read, study, and direct your energies toward better understanding parents of handicapped children and their counseling needs. Parents of handicapped children vary considerably in their need for

counseling, but when they do seek help, they are experiencing problems and need help in finding a possible solution.

Helpers have a unique opportunity to assist troubled parents in attaining productive and rewarding behaviors. Understanding parental feelings, attitudes, and values will enable the helper to effectively intervene in self-defeating and inappropriate behavior patterns. This section is, therefore, directed toward your helping parents to learn and develop appropriate behaviors and coping skills.

# 7

## The Family and the Exceptional Child— Overview and Impact

*After mastering the material in this chapter, you should be able to*

1. Discuss the concept of the family unit and relate this to the task of being parents of a handicapped child.
2. Briefly describe stress and identify stressful situations that may occur in the family of a handicapped child.
3. Discuss the general effects of a handicapped child on the family.
4. Identify and describe some possible effects of a handicapped child on siblings. What factors might lead to sibling maladjustment?
5. Use strategies that may help siblings cope more effectively with their handicapped brother or sister.

*The purpose of the family unit is to create a vessel or environment for the development of mature, fully-functioning individuals.*

—Laura Sue Dodson

*The effect on family units of the addition of a handicapped member varies widely, despite the gloomy, general descriptions by physicians and mental health workers of increased stress, marital disputes, and sibling antagonism.*

—Linda Sterupte and Richard O. Bell

**T**he impact of an exceptional child on a family is aptly described by Hardman, Drew, and Egan (1984):

Nowhere is the impact of an exceptional individual so strongly felt as in the family. The birth of a disordered infant is likely to alter the family as a social unit in a variety of ways. Parents and siblings may react with shock, disappointment, anger, depression, guilt, and/or confusion, to mention only a few. Relationships between family members often change, in either a positive manner or a negative manner. The impact of such an event is great, and it is unlikely that the family unit will ever be the same. (p. 419)

The purpose of Chapter Seven is to identify and discuss the specific impact of an exceptional child—especially a handicapped child—on the social system of the family unit. Particular emphasis is placed on examining how changes in one family member can consequently affect the entire family system.

### **THE HANDICAPPED CHILD'S IMPACT ON THE FAMILY UNIT**

It is important to begin our discussion by defining the term *family unit*. Dodson and Kurpius (1977) give the following definition:

The family unit, broadly speaking, is a unit of people who live together and share life's basic day-by-day functions. Throughout history, humanity has demonstrated need for such a core group, yet also has demonstrated need for each individual member to grow. These dual, sometimes contrasting human needs create the paradoxes of the family unit, in which exist struggle for separateness and togetherness, differences and sameness, protection and freedom, support and independence. The purpose of the family unit is to create a vessel or an environment for the development of mature, fully functioning individuals. The paradox of the family situation is that this end is achieved

only as the individuals in the family are contributing to and participating in the family process. (p. 3)

iamberg (1985) offers a similar view:

The family performs the primary function of socializing the child from birth through at least adolescence. This process of socialization is accomplished through mutual interaction between parent and child. These interactions include the transmission and interpretation of cultural standards of values and behavior. The family can be viewed as a dynamic system that changes over time, as do its members. (p. 249)

These definitions, then, characterize the typical family unit. Now imagine the arrival of a handicapped child into that unit. Although parental reactions to the birth or arrival of a handicapped child into the family are discussed in a later chapter, what is important to understand at this point is that such a traumatic event can create additional stress within the family. Lombana and Lombana (1982) emphasize that although counseling circumstances are diverse, certain types of parents, such as those with handicapped children, appear to experience more stress. Brammer (1979) defines stress as a condition characterized by physiological tension and a persistent conflict of choices that pressure the person to reduce the tension and achieve equilibrium. Holmes and Rahe (1967) studied stress by placing an objective value on certain situations that directly affect a person's physical health. These stressful events, ranging from the death of a spouse to minor violations of the law, were scaled and assigned a value. These rankings are presented in Table 7.1 on page 112.

Noting stress items 11 and 14 should indicate the possible impact of the arrival of a new family member or a change in health of a family member. Stress will increase when that newly arrived family member has a mental, physical, or sensory handicap. Schleifer (1982) poignantly describes how the hopes of parents expecting their healthy firstborn are often shattered:

Couples have daydreams and images of what this new stage of parenting will bring. Joyful images are modified by the real experiences of parenting. The couple must also make a different kind of commitment to each other and the baby. They will have to resolve how they will work together so that the interests of each can be met. The birth of a child with a serious difficulty complicates this process. First the images of themselves as parents are likely to be changed. This time that would have brought pleasures brings doubts and worries. The ordinary difficulties of helping any child grow arouse frustration and helplessness at some point in all couples. But when parents are having greater difficulty, they find themselves preoccupied with their own efforts and especially their feelings of frustration. (p. 44)

Ehlers, Krishef, and Prothero (1977) note that even parents who have had close contact with retarded children often find themselves in a state of shock when told that their own child is retarded. The counselor's aware-



*The family performs the primary function of socializing the child.*

ness of this shock and finding ways to deal with it separate the counseling of parents with a retarded child from the counseling of most other parents.

Similarly, Robinson and Robinson (1976) offer another perspective on the effects of a handicapped child on the family:

The path of parenthood is never completely smooth. Patience, understanding, ingenuity, good humor, and strength are demanded in large measure from the parents of any youngster. For the family of a retarded child, however, the situation may be more complicated and more hazardous, and the rewards of parenting more likely to be lost sight of. The child's handicaps; his slow development; the special arrangements needed for his physical care, training, and companionship; the disappointments and the lost dreams—all combine to create pressures which tend to disrupt family equilibrium. Added to these pressures may be financial problems, tensions created by the child's immature self-control, handicaps in communication, and the parent's own lingering doubts about their upbringing practices. Thus, the relationship between a retarded child and his family is potentially more complex and ambivalent than the ordinary one, and more intense and prolonged. (p. 413)

The presence, realization, and impact of a handicapping condition is usually felt by all members of the family because of the emotional, social, educational, and economic demands placed on them. These demands and

TABLE 7.1 Stress rankings

Stress					
Rank	Life event	Mean			
1	Death of spouse	100	24	Trouble with in-laws	29
2	Divorce	73	25	Outstanding personal achievement	28
3	Marital separation	65		Wife begins or stops work	26
4	Jail term	63	26	Begin or end school	26
5	Death of a close family member	63	27	Change in living conditions	25
6	Personal injury or illness	53	28	Revision of personal habits	24
7	Marriage	50	29	Trouble with boss	23
8	Fired at work	47	30	Change in work hours or conditions	20
9	Marital reconciliation	45	31	Change in residence	20
10	Retirement	45	32	Change in schools	20
11	Change in health of family member	44	33	Change in recreation	19
12	Pregnancy	40	34	Change in church activities	19
13	Sex difficulties	39	35	Change in social activities	18
14	Gain of new family member	39	36	Mortgage or loan less than \$10,000	17
15	Business readjustment	39	37	Change in sleeping habits	16
16	Change in financial state	38	38	Change in number of family get-togethers	15
17	Death of close friend	37	39	Change in eating habits	15
18	Change in line of work	36	40	Vacation	13
19	Change in number of arguments with spouse	35	41	Christmas	12
20	Mortgage over \$10,000	31	42	Minor violations of the law	11
21	Foreclosure of mortgage or loan	30			
22	Change in responsibilities at work	29			
23	Son or daughter leaving home	29			

SOURCE: Chart originally published in "The Social Readjustment Rating Scale" by T. H. Holmes and R. Rahe, 1967, *Journal of Psychosomatic Research*, 11, pp. 213-218. Reprinted with permission of Pergamon Press, Inc.

Obligations make families of handicapped children particularly vulnerable to stress. Crnic, Friedrich, and Greenberg (1983) state that "the impact of mental retardation is never restricted to retarded individuals; members of the immediate and extended families are affected to varying degrees" (p. 25). Gallagher, Beckman, and Cross (1983) extensively reviewed literature that links a wide variety of factors to parental stress and discovered that stressful factors may come from the handicapped child, the parents, the sib-

lings, the extended family, and even the institutions designed to help the child.

Smith (1984) identified several types of stress commonly associated with parenting a handicapped child. These potential stresses further illustrate the additional and unexpected pressures and responsibilities that parents of handicapped children must deal with. These possible stresses consist of the following:

- ☐ Dream of child shattered
- ☐ Child looks different
- ☐ More attention required
- ☐ Routine caregiving is more difficult
- ☐ Attitudes towards handicapped
- ☐ Exposed to frustrations and humiliations
- ☐ Lowered self-esteem
- ☐ Less time for siblings
- ☐ Spouses have less time together
- ☐ Friends uncomfortable/drift away
- ☐ Avoid situations/social events
- ☐ Fewer rewards for being a parent
- ☐ Separations/disruptions of parent-child relationship
- ☐ Reactions of relatives/family
- ☐ Lack of specific information
- ☐ Increased costs for medical, special equipment, and trips
- ☐ Conflict in opinions
- ☐ Parents' expectations often inappropriate
- ☐ Break in communication/relationship with child
- ☐ Unknown questions regarding future
- ☐ Vulnerable child

### ONE PARENT'S PERSONAL ACCOUNT

Reading the following account of a parent's personal experience gives us significant insight into the effect of a handicapped child on the family. Carole Hosey (1973) presents a readable and self-explanatory account that needs no further comment.

In this account of my son's life in our family circle, I hope to present a strong case for the preservation of every human being and the inclusion of every child in a loving family when possible.

Stephen is 11 years old, profoundly retarded, cerebral palsied, and epileptic. He doesn't walk or talk and he probably never will. He does not understand speech and has few ways to communicate his needs. Stephen also has both visual and auditory perceptual impairment and a variety of seizure dis-

NOTE. From "Yes, Our Child Is Still With Us" by Carole Hosey, 1973, *Children Today*, 2, pp. 14-17, 36.

orders. Although some of the disorders are well-controlled, he has dozens to hundreds of small drop seizures daily.

Stephen is a handsome boy, although he has a wasted, underdeveloped and poorly muscled body. He does not whine, whimper, or cry except when in extreme pain. He has a very sweet expression and a gentle personality.

In this account of his life, I would like to emphasize that I realize that the qualities of each child make him or her—to a greater or lesser degree—easier to take care of in the home. I am not foolish enough to think that every severely handicapped child will be as comparatively easy to take care of as Stephen.

I have longed many times to be able to describe to a doctor how we feel about our handicapped child. I am in my late 40s and my husband is in his early 50s. We have a 20-year-old son and two daughters, aged 16 and 18, living at home, as well as a married daughter. The children were 11, 9, 7, and 5 when Stephen was born. My husband and I married young and adopted our first two children after several childless years. Then I gave birth to our third child, a normal and very intelligent daughter. A short time later, we adopted our fourth child. And then, when I was 37, I gave birth to Stephen after an uncomplicated pregnancy. But the delivery was induced and precipitate, and much later we were told that lack of oxygen was the probable cause of enormous damage to his central nervous system.

Stephen's color was not normal following birth; his lethargy was profound and his sucking ability so poor that his weight fell almost a full pound during his first five days. Nevertheless, Stephen was discharged from the hospital to us as "a normal male infant."

As his first year came to an end, however, I realized that his inability to turn over, sit up, or crawl was not to be explained by his chubby weight or crossed eyes. When he was 14 months old, we asked for comprehensive testing. I stayed in the hospital with Stephi during the week of tests. Each evening the pediatrician would come and tell me the results of the tests and, because I was naive, I was pleased as he reported each negative result. It was only at the end of the week, when he explained, that I started to understand the horror of the situation. The doctor said he had done the tests hoping to find something, anything, that was correctable. But as each of the tests were negative, he realized that we were faced not with a thyroid deficiency or something of that nature but with an undeterminable amount of brain damage and a very crippled little boy. During that week in the hospital I had spent many hours fighting panic—swinging upward when I got the details of a test result, and then down again when I made myself face the facts, as I had begun to face them the day I first called the pediatrician before one of Stephen's well-baby check-ups and told him I thought Stephen was retarded and asked him to talk honestly with me.

I was told there was nothing to be done but wait and see how he developed. I took Stephi home from the hospital to the family. We were in a better position than many young couples who have this experience. First of all, we had raised four normal children, which was a comfort. Secondly, we were both of a mature age, not a young couple untested by problems. But I will always remember my feeling of numb despair. I didn't cry or give much

external sign of my inner hysteria but I felt that I would never be able to adjust to this situation.

The shock of the birth of a child like this doesn't come all at once. It's worse in some ways than the death of a child because you gradually realize that this child is never going to live in the fullest sense of the word. It is only after months or years pass that you find out how your family will be affected.

It was difficult for us to absorb the first shock, which is truly physical as well as mental. We were numb, we could scarcely walk about and do our normal day's work, or talk to other people. Still, we had no agonizing decision to make at this point. We loved Stephi, he had been a part of our family for more than a year, and no one would have suggested, even if it had been possible, to allow him to die. He was living and he was healthy then. The shock consisted of knowing that we had a child who would never grow up. He might have a very long life, but he would not experience any of the pleasures of adulthood, such as fatherhood, nor the other lovely pleasures of a normal life.

I feel strongly that no couple, no matter what their age or experience, can make a wise or even a fully conscious decision at a moment like this. I feel that unless a decision is absolutely imperative because of life or death alternatives, it should be postponed. I am firmly convinced that parents' assertion of their instinct to love and cherish their child is essential to a family's mental health. I think that at the moment of first knowledge of their child's damage this instinct may be stunned by the pain they are experiencing. But I know that if someone stands by and encourages them to love the child and, if possible, to take the child home, it is going to help in many ways for the rest of their lives. If this instinct to love and cherish the child asserts itself, then I think that they can make a loving decision about him later on. This may be later in terms of a week, or years, but if they have allowed their natural parental instinct to be developed, they are going to make it *because* they love the child and they will not, instead, have to live with a memory of rejection. It is better to remember in the years to come that you did everything out of love for your child, and not because you lacked courage. If parents have to institutionalize the child, soon or years later, it may be very painful, but they will be comforted by knowing that they loved him.

Because we had to travel with my husband's job in the years following Stephen's birth, we had the opportunity to see more doctors with Stephi than the average family could or would. We found that, as time passed and Stephen's disabilities became more apparent, doctors were *still* explaining to us that he was retarded. Since this would have been obvious to anyone at first glance, we could only conclude that they were really saying, "Why do you still have this retarded child with you?" Or they would be more forthright about it and say, "A child like this is damaging to your other children. You should see about an institutional placement for him. Do you have him on a waiting list? You have your own lives to live."

From the time we were given our first child, our lives had involved our children and they were never to be separated totally from any of them. So now we questioned why our lives and emotions should be separated from the most helpless of all of our children. Doctors did at times express pity and I have heard many other parents of retarded children say rather belligerently

that they don't want pity. I don't feel this way. There's nothing wrong with pity as far as I'm concerned; in fact, *I* feel very sorry for myself at times. I think that honest parents of a child like ours do feel that they and certainly their child have had a damn poor shake out of life. It *is* a tragedy! It's heart-breaking. But our children are here. They live. They must not be rejected like broken toys.

I've often wondered why doctors didn't give me credit and support for an intelligent decision to give my child the safe-keeping that I knew I could give him for as long as it was possible for me to give it to him. But so many times I've been made to feel that I love Stephen almost illegally and certainly unintelligently. We were told by one doctor that Stephen was not a productive member of society; therefore, we did not have the right to take family time, money, and energy away from our other four "productive members of society" in favor of Stephi. We had a strong family feeling that each child, as in *all* families, naturally gets the time and money and energy that he or she needs from parents. As far as society goes, I think one of the greatnesses of our country is that the benefits, the fruits of our country, don't go just to the taxpayer, but to all the people. And it is the same in a family. As far as our other children are concerned, we couldn't believe that his presence was going to be detrimental to them. They seemed to be growing normally. They dearly loved Stephen and still do. They don't hesitate to bring their friends home and discuss their little brother. In fact, when one of our daughters was in the fourth grade and her class was discussing mental retardation, she asked me if she could take Stephen in for "Show-and-Tell." The teacher agreed, and I felt that it was beneficial to the children. Handicapped children have been kept in back rooms and in special classes, hidden away, so naturally they are objects of curiosity to be stared at. When they are permitted to enter as much of normal social life as possible, there will be a greater understanding of their problems.

The sorrow of Stephen's condition is a lasting thing, something that flares up at strange times. It hits both of us, my husband and me, many times. Once when I was driving through the mountains of Switzerland, it overpowered me—knowing Stephi would never feel the beauty of approaching evening in the mountains. And at other times, perhaps during a beautiful piece of music that I know that he will never understand. . . .

The day-to-day care of Stephen is not the difficult part. I guess the most difficult thing about these children is facing their future. We can protect him now, but unlike most couples who enter their later years with a fair amount of serenity, looking forward to retirement and the easing of family responsibility as their children leave home, we have one child who will never be independent. We are able to care for him lovingly now, but this isn't enough. He shouldn't be well cared for only during our lifetime, but for all of his. And most families probably find the worst of the nightmare, wondering where their child will live out the end of his life, praying that he won't be neglected, malnourished, or cared for by insensitive people.

I often wondered when Stephen was very young and not having any medical problems how I would have felt if I had had a child who had been diagnosed as gravely damaged at birth and I had had to make a life-or-death

decision. Later in Stephen's life, we went through a series of medical crises—several episodes of chain epileptic seizures, months of allergic drug reactions, weeks of forced feedings when he lost his swallowing reflex and wasted almost to death, and, just a year ago, a day and a night of almost fatal hemorrhages after surgery. It was a testing period for me because, as I saw him through those periods, there was no doubt about my feelings. I wanted him to live, just as I would want my normal children to survive.

Stephen is currently enrolled in the Intensive Training Unit for retarded-multihandicapped students at the Montgomery County Association for Retarded Citizens in Silver Spring, Maryland. We found through the years that meeting Stephen's need for training in the basic life skills required the most determined effort on our part. Less damaged children are sometimes accommodated in public school systems, but we had to insist repeatedly that he not be ignored because of the multiplicity of his problems. The quality of his adult life was going to depend on our being able to do something about our conviction that feeding himself was better than being fed, and learning to sit upright in a wheelchair was preferable to lying in a crib for the rest of his life.

In writing all this, I have tried to present the problems of a family with a handicapped child. This is easier to do than to explain the plus side of our life. There is *so much more* of that, but it is harder to put into words. Stephen has given us a great deal of positive happiness. He isn't just tolerated. When he is ill, we pray that he will survive. We had a family celebration at the end of his ninth year, the first year he had not had a stay in a hospital. The family was thrilled when he brought his first bite of food to his mouth by himself, and when he learned to stand up from his wheelchair. I think our children have gained in compassion and maturity. They are more aware than many of their contemporaries of how precious a normal life is, how wonderful an undamaged intellect, and how lucky they are to have whole bodies. Great patience with a slow child can leave you with a sense of warmth and pride. I am sure it is difficult even for a doctor who works with children like Stephen every day to try to imagine himself a parent of a seriously damaged child. I couldn't do it before I had Stephi. I was totally unprepared. But there are no regrets now. I wish very much that Stephen was a normal child. But as long as he is the way he is, I am glad he is ours. I wish that every father and mother who has a handicapped child born to them could be given a chance to love their child. (pp. 14–18, 36)

Heward and Orlansky (1984) indicate that the birth of a handicapped child or the discovery that a child has a disability is unquestionably an intense and traumatic event. Parents can differ widely in their reactions, and the helper or counselor should always be aware of this. Berdine and Blackhurst (1985) list such factors as religion, socioeconomic status, severity of handicap, parental knowledge, and order of birth that can all affect the parental responses of frustration, fear, disappointment, and uncertainty. The reactions and subsequent behavior of parents toward their handicapped child are complex issues—sweeping generalizations are of little or no value. Contrasting views and opinions about parental reactions exist, however.

Kneedler, Hallahan, and Kauffman (1984), for example, feel that despite the problems and the emotional turmoil, the ultimate impact on a family of having an exceptional child is minimal. These families do experience great stress, but they also learn to cope, sometimes better than other families. Kneedler, Hallahan, and Kauffman add that many families become closer and stronger than they might have been otherwise.

Suran and Rizzo (1983) reiterate the idea of the importance of the family unit and its functioning. They state:

It is also important to maintain a developmental view of family organization and functioning. A family is a dynamic system of relationships in which each member is continually adapting to ongoing changes in other family members. Tensions or problems affecting any member of the family inevitably affects other members. For example, a child's disability will, in some fashion, affect every other family member. In most cases, the family will adapt itself to the child's problem through changes in attitudes and behavior. However, whether these adaptations are positive and satisfying or painful and stifling may well depend on a variety of obvious and subtle factors. We can readily see the impact of social or educational background, parental maturity, or financial security. Less obvious factors influencing the family system are the attitudes and reactions of grandparents and other relatives, neighbors, physicians, teachers, and other professionals. While some of these factors are beyond influence, it is critical that helping agents ensure that their impact is positive and growth promoting. Thoughtful attitudes toward the special conditions of childhood and care in communicating with parents can have crucial results in moving a family in the direction of optimism, growth, and mutual satisfaction. (p. 60)

In order to gain a balanced perspective of the impact an exceptional child will have on the family, it is important to learn the viewpoint of parents of these children. Here, Harra (1975) presents just such a viewpoint:

Parents, we're pretty terrific! We need to tell each other that periodically. At least once a day would be fine, but we'll settle for every now and then. We can't put our wares on a table like a salesman and we have no professional research papers to present. Unlike politicians, we dare not make grandiose promises about the future. We see the results of our labors in ways that go unnoticed by most others, but are vastly significant to us—we see progress in our children. Sometimes it's a new word learned or pronounced properly, sometimes it's a ball successfully thrown and caught, or it may be the absence of a tantrum. We know that these little things have enormous significance.

### ***We are Pioneers***

In our own way, we're all pioneers. How many of us knew anything at all about disability before we were confronted with the condition in our child? How much have we learned since then? A great deal. Not in professional terms,

perhaps. We don't have the professional's clinical training and broad factual knowledge. But we know our own children exceedingly well. Ours is an exquisite awareness of how a specific child's disability interacts with everything else he is and tries to be.

Some of us were first told of our child's difficulty by a professional. Others of us knew something was wrong and sought help. Whatever the circumstances, we depend on professionals to help our children. Each of us is indebted to more than one such person who has been on the scene at the right time with the right help. This much is clear. What is not so clearly established yet is the extent to which we, the parents, can be of assistance to professional workers in a cooperative effort to help our individual children.

### ***We Orchestrate Our Children's Care***

It's slowly being recognized that parents play a unique role in their children's care in several respects. First, we make the final decision about which professional to engage with our child. Second, we have a special kind of information to share with professionals about our children, for only we observe them at home in the routine of their everyday life. Third, when resources are lacking, we are the catalysts, the prime movers, in seeing that resources—educational, medical, recreational or social—are developed. Fourth, I would guess that most of us are engaged in some kind of remedial effort with our children at home, supporting their development and enriching their learning through directed efforts or weaving this "instruction" in informally during the day's activities. We also carry through prescribed medical therapies or physical therapies of one sort or another.

Finally, it is we, the parents, who have the abiding responsibility for our child throughout his dependent life, whether for a few years or well into his adulthood. Often, this ongoing support and effort by parents is what makes the difference between whether a child ultimately "makes it" as an adult, or not. The professional's help, though vital at each point, is transitory. No matter how well or poorly equipped we are to meet the ongoing demands, we bear the responsibility for orchestrating the help our child needs—and the care our child gets. It's a difficult job. We can't afford the relief and release of total objectivity. Too much is at stake—the quality of our child's present and future life. And we can't leave the problem at the office at the end of the day. Our home *is* our "office."

### ***Our Worry Is Appropriate***

Our task is made all the more difficult when we meet the professional, relative or friend who tells us with all good intention, "Stop worrying!" or, "You're worrying too much!"—which is another way of saying, "You're over-anxious." And this makes us worry all the more, because we know we haven't succeeded in communicating the urgency of our child's situation and need. When we're in a dialogue with a professional, this communication gap can have serious consequences.

Too often we hear of parents who try to bring a troublesome physical condition in their child to the attention of a pediatrician who dismisses it,



saying "He'll outgrow it," only to be confirmed later when it may be more difficult (or too late) to correct it. How many times have we heard stories of parents trying to get help at school for a child whose performance is characterized as a "behavior problem" or "not trying hard enough"? The parents know from their observations at home how hard their child is trying; his "problem" behavior is a symptom, not a cause, of his frustration and failure. Then, upon testing, the child is discovered to have a perceptual handicap, petit mal epilepsy, or a visual or hearing disorder of some kind. When parents see that their child is in trouble, but that help is not forthcoming, you can bet they'll get anxious. When parents insist on bringing problems to the attention of professionals, are they "over-anxious"? Or properly concerned?

### ***Our Concern Changes As Our Children Change***

When our child's difficulties are recognized and supportive help is available, that doesn't automatically dispel all anxiety. Chronic conditions don't disappear with remediation, although they may become more manageable. Each new situation, each new stage of life, presents a forest of unknowns to be dealt with. A change of school or a new teacher, an infant in the family, a new child in the neighborhood—any of these events can be a special challenge to our children. Or, the change may be internal, generated by a new stage of development. The "Terrible Two's" are the "Terrible Two's," no matter what else the child is dealing with, or what his chronological age when he arrives at that stage. Adolescence is a head-holder for everyone. The difficult task of establishing a sense of identity is blurred further by disability.

As each new situation or development presents itself, the parent is again a pioneer, trying to hack out a new path, looking for a familiar trail. The fact that many of our children cope as well as they do is a tribute to their inner strength and resources, *and ours*. The fact that many fail, or feel that they do, is a sad commentary on the lack of ready outside support and resourceful help. We know our children can "make it" when given the opportunity to do so.

### ***How Others View Our Concern***

It is curious that others look askance at our concern and special effort in behalf of our children. When there's a new story about a child trapped down a well or requiring blood donations, total strangers will respond and offer help. These people are applauded for their concern and generosity. And so they should be. They are responding to a recognized need. However, when a parent makes a similarly dedicated effort in behalf of her own child whose needs *she* clearly recognizes, she's told "You're over-anxious. You're worrying too much." Who is more entitled to worry? A complete stranger or a parent?

Sometimes, these discouraging assessments can be completely deflating. Often, they inhibit us from persevering with our efforts. We may feel intimidated, foolish, or guilty. One of the reasons we're put on the defensive is because of the social stigma attached to the terms "over-anxious," "anxious" or even "worried." Somehow, if one is visibly anxious about something, it is all too often seen as a sign that one must be "neurotic" and therefore incom-

petant. Who wants to be considered incompetent precisely when she is trying to enlist help for her child? *The last thing we should do is to stop trying.*

### ***What is Anxiety?***

Let's stop and take a good look at this nasty term *anxiety*. This is hard to do because anxiety is a shifty word. In clinical terms, it has to do with fear that seems "unrealistic." For instance, some people treat a sneeze as if it were pneumonia, or a momentary pain as if it were a symptom of cancer. But we can dispense with the clinical phenomenon, because what we're talking about here is entirely different—namely, proper concern with the problems which encumber our children. This is something very realistic.

In everyday usage, anxiety means fear or apprehension. As we all know, when a child is in difficulty, whether the difficulty is considered "minimal" or severe, there is due cause for apprehension. There is no such thing as a "minimal" disability if it's a condition which interferes with a child's normal development and threatens his future. Parents have no choice. We worry about it, whether it's a heart condition or stuttering, an emotional disturbance or poor coordination, autism or a hearing impairment.

### ***Invisible Heroism***

What about the advice to "Stop worrying!"? This is about the most outlandish combination of words I can think of in this context. One might as well tell a movie audience to stop worrying about the heroine tied to the railroad tracks with a locomotive coming around a blind curve. As long as a problem remains unresolved, one for which we feel a responsibility, it's human nature to be in a state of *active concern*. And when the problem involves our own child who has special difficulties, we worry. We'll stop worrying when we know our children are secure. It's that simple. Moreover, it's a waste of energy to worry about the fact that we're worrying. So, most of the time we respond. Our anxiety doesn't overwhelm us—although it has that potential. Instead, our anxiety makes us alert and ready to continue. It's one thing to summon energies and resources in a crisis situation and to take action—a man rescues a child from an icy lake and becomes a hero. But it also takes courage, resourcefulness and devoted determination to be an everyday hero or heroine. And this invisible heroism is what goes on in families with children with special needs. These rescue operations in the home are usually not matters of high drama, but of tedious dailiness. It may mean preparation of a special diet, every meal, every day. It may mean giving medication several times a day. It may mean giving medication several times a day, every day. Or giving a patient answer to an impatient child. Or giving the same answer or showing the same process for the 800th time to an uncomprehending child. It means long waits in a doctor's office or clinic to see a physician for a few brief minutes. Or conferences with teachers, principals, athletic coaches, camp directors or therapists many times during the year. It means trying to re-establish some equilibrium in a family put off-center by the time and attention absorbed by the child with the greater needs.

This kind of effort goes on every day of every week of every year. There are no headlines or medals. But this kind of heroism is as vital to our child's well-being as his being rescued from an icy lake. Because as we all well know, without proper and sufficient ongoing support, our children do drown. They drown in their own mistrust of themselves and others, in their sense of failure and frustration, or in a condition which (if allowed to) envelops and suffocates their individuality.

We get worn down by the unending demands and pressures. The very fact that these responsibilities are tedious, repetitive and undramatic, however essential, makes us bored and irritated with carrying them out. Then, on top of everything else, we start to worry that we don't love our child enough. Such worry confuses the issue. We're entitled to notice and resent the internal bruises we suffer from the anxiety that bangs around inside, and the aches from the ongoing chores. But this is distinct from the love for our child and the commitment to him which keeps us at our tasks.

***We're In This Battle Together***

Perhaps one of the most difficult aspects of living with a child whose problems are not easily resolved is the inevitable sense of isolation. You're aware that to the world at large, you look as if you're doing perfectly ordinary things—going shopping, taking care of work in an office. But your thoughts and feelings are really elsewhere—on an invisible battlefield fighting an undeclared war that only you can see, hear and feel. In a "real" war situation, at least everyone is aware of the same dangers and appreciates the stress each is experiencing. How do we answer the casual conversation-opener "What's new?" Not knowing how to begin to explain, we find ourselves answering "Oh, nothing much." The fact is, we're all in the same battle together—the ongoing struggle to do the best we can for our children under difficult circumstances. The message in all this is "Trust yourself!" Because of your close bond with your children, because you have been alerted by your concern to act on their behalf, because you know them "subjectively," you do a job for your children which no one else can do. Fellow parents, you're okay!

***EFFECTS OF A HANDICAPPED BROTHER OR SISTER ON SIBLINGS***

Recognizing the added stress of a handicapped family member as well as the power of the family as a socializing agent, Stanhope and Bell (1981) remind us that educators and mental health professionals are increasingly involving both parents and siblings in the treatment of children with special needs. One school of thought is that brothers and sisters of the mentally retarded are "forgotten children," and counseling these children is a completely new field for professionals. Much of the current literature about the family of the handicapped child now includes the impact on normal siblings.

Seligman (1983) offers the following viewpoint on sibling impact:

From an empirical point of view, the question of whether normal siblings are not affected, helped, or harmed by the presence of a handicapped brother or sister is largely unanswerable. Even in exceptional families where a child experiences emotional difficulties, it is virtually impossible to ascertain which factors have contributed to the situation. The emotional climate in some families is so stressful and unstable that sibling maladjustment is predictable based solely on family dynamics irrespective of the presence of a handicapped child. (p. 529)

Seligman also notes that a number of isolated factors contribute to sibling maladjustment. Table 7.2 lists the factors cited by Seligman.

**TABLE 7.2** *Factors contributing to sibling maladjustment*

Factor	Seligman's Comment
Responsibility	The extent to which a sibling may be held responsible for a handicapped brother or sister bears a strong relationship to the perception and feeling children, adolescents, and adults have about their handicapped siblings and parents.
Catching the disability	In the wake of a disability, young children may be concerned about "catching" the disability. Anxiety about this is heightened when siblings learn that their handicapped brother's or sister's disability was caused by a disease like rubella or meningitis.
Anger and guilt	Siblings of handicapped children may experience anger in larger doses than siblings of normal brothers and sisters. Whether siblings harbor or openly express their feelings of anger and resentment depends on a complex arrangement of factors.
Communication	Lack of communication within a family over a child's disabling condition may contribute to the loneliness normal siblings experience. Siblings may sense that certain topics are taboo and that "ugly" feelings are to remain hidden.
Parental attitudes	There is some evidence that normal siblings are affected by their parents' attitudes toward the handicapped child. The degree of open communication about the afflicted child in families seems to be an excellent barometer of parental attitudes.



*Siblings are becoming increasingly involved in the treatment of children with special needs.*

Wasserman (1983) observes that unfortunately there is little professional literature that focuses on the relationship between retarded and non-retarded siblings. In reviewing the studies that do exist, however, he has identified four specific concerns that have been expressed by sibling groups:

1. *The need for information*—there was frequently a startling lack of information about the handicap, its manifestations, and its consequences.
2. *The need to understand and work through emotional reactions*—while many siblings struggle with fears, anxiety, and guilt, the emotional reactions of the siblings studied are inconsistent.
3. *Self-identity and roles*—the development of a separate identity from a mentally retarded sibling seems, based on Grossman's (1972) and Schreiber and Feeley's (1965) work, to be very important to normal siblings. Role identification is also a problem. For example, what is a normal sibling's role with respect to a mentally retarded sibling?

4. *The need for effective coping strategies*—the siblings frequently expressed the need for strategies to cope with their relationship with their mentally retarded brothers and sisters. Because of the importance of these concerns, Wasserman proposes counseling services of two types—direct and indirect. In the first type, a counselor works directly with siblings of the mentally retarded. The second type involves counseling siblings indirectly through the parents.

Hardman, Drew, and Egan (1984) offer an insightful view of sibling relationships.

Siblings who learn that they have an exceptional brother or sister are frequently encumbered with many kinds of concerns. Such questions as "Why did this happen?" "What am I going to say to my friends?" and "Am I going to have to take care of him all of my life?" are common. Like their parents, siblings want to know and understand as much as they can about the condition of the impaired sibling. They want to know how they should respond and how their lives might be different as a result of this event. If these concerns can be adequately addressed, the prognosis for positive sibling involvement with the impaired brother or sister is much better. (p. 435)

According to Schwartz (1984), it is also important to understand that siblings of the exceptional child, as well as others, often take their cues from parental behavior and attitudes. Siblings may accept or reject the "special person" depending on their parents' attitude; they may certainly be resentful of parental overindulgence of the exceptional child. Schwartz concludes that realistic acceptance of and participation in caring for the handicapped child creates a happier and more productive family situation.

When reviewing literature from 1950 to the present, Schreiber (1984) found only five articles dealing specifically with social work practice with normal siblings of a mentally retarded child. In all five articles, the purpose was to help the normal sibling deal with an assumed difficulty arising from the presence of a retarded child in the family. Schreiber made two relevant points for *all* helpers who work with siblings and the family of mentally retarded or handicapped persons:

1. The articles as a whole draw the attention of the profession to a neglected area of practice. All of them demonstrate the attributes of a specialized practice and reflect the need for the worker to be able to deal with both basic and special needs of individuals and families.
2. The encouraging results of the practice efforts discussed in these articles suggest some areas for further inquiry. The greatest need is for long-term studies that offer greater understanding of the processes of childhood, adolescence, and adulthood that affect sibling and family interactions. Such studies would help to draw attention to the many kinds of interactions within families, and to decide when intervention would be most appropriate. Variables to be considered include socioeconomic status, race and ethnicity, family life-styles, childrearing patterns, and different kinds

of handicapping and stress-producing conditions. The number of siblings in a family, the age differences among them, and the kinds of alliances they build are other factors that need to be studied. The major focus of practice and research efforts should be on the ways that different kinds of siblings develop in different family environments.

### CHAPTER SUMMARY

A counselor who works directly with parents of exceptional children should understand the dynamics of family relationships. Establishing effective parent/professional relationships depends on your ability and efforts to understand how the family copes with sudden unexpected disappointment—the presence of a handicapped child in the family. Helpers should be able (as best they can) to understand the impact a disabled or handicapped child has on his or her family, including the child's normal siblings.

Counselors should be aware of the possibilities of *the extended family*, a term frequently used to describe other family members such as grandparents, brothers and sisters of parents, or other close relatives. These relatives may become part of a resource network that can offer support, comfort, and understanding to the parents of a handicapped child. Beyond the extended family, there is a growing network of people who share traumatic experiences with others who will experience or have experienced the same thing. Networking, then, is the process of linking people to each other as resources—assisting, supporting, and helping others find the services and information they need. In many instances, parents want to talk to other parents who have coped with similar difficulties. A mother of a handicapped child describes the togetherness networking provides:

If you think about a family and what it is, you realize that it's not just flesh and blood, but the fact that over the years, you have all shared something, and that is what makes you united. You don't even have to talk about these experiences. They are there. In our case, we have a sense of family because we share with each other something that is unknown to other people who do not have a child who is handicapped. You don't even have to talk about it, but when I am in a group of people with handicapped children, there is something that is unspoken between us which each of us knows and feels. (Witherspoon, 1980, p. 1-B)

### ACTIVITIES, EXERCISES, AND IDEAS FOR REFLECTION AND DISCUSSION

1. Should brothers and sisters have responsibilities in caring for their handicapped siblings at home? At school?
2. Do you agree or disagree with the following statement: As with all children, a handicapped child's most important asset is the support and nurturance of his or her family. Explain.

3. Will some types of families, such as single parent families, teenage parents, poor families, or those without extended family or friends, find it more difficult to cope with a handicapped child than other kinds of families? Why?
4. Families differ significantly in their ethnic, racial, and religious backgrounds as well as economic status. How might these factors affect the family of a handicapped child?
5. As counselors, how can we help siblings develop greater maturity, tolerance, patience, and sense of responsibility toward their mentally retarded brother or sister?
6. Interview a brother or sister of a handicapped child. Find out their most notable concerns, frustrations, and adjustments.
7. Interview the mother and/or father of a handicapped child about their primary concerns and reactions to the child; what impact did the child make on the entire family?
8. How can counselors and helpers best prepare themselves to understand the impact and dynamics of a handicapped child on the family?

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